

The Texas Birth Defects Monitor



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from the Director

Completion of the Texas Neural Tube Defect Project—Next Steps

The Texas Department of Health (TDH) is pleased to announce that the Texas Neural Tube Defect Project (TNTDP) will conclude the data collection phase of its important study at the end of the summer. However, TDH will continue to conduct various projects to prevent neural tube defects statewide.

In the fall of 1992, the Centers for Disease Control and Prevention (CDC) and TDH started the TNTDP for the 14 counties along the Texas-Mexico border. The TNTDP comprises three components: a surveillance initiative, a folic acid intervention (recurrence prevention), and a case-control study, with the following objectives:

- To determine the birth prevalence of neural tube defect NTD-affected pregnancies among residents of the 14 border counties through active surveillance.
- To decrease the risk of recurrent NTD-affected pregnancies in high-risk mothers by providing them with education and folic acid.
- To identify risk factors for NTD occurrence, particularly on the border, through a case-control study.

There have been three teams along the border performing all the tasks required for this project. These teams were based in Harlingen, Laredo, and El Paso. To ensure that sufficient data were available, data collection for the study was extended two years past its initial completion date, with additional support from CDC and TDH. These data collection efforts will formally conclude on August 31, 2000. TNTDP will spend the coming year cleaning, analyzing, and publishing data.

The TNTDP has already had a major impact on the health and well-being of children along the Texas border. From 1993-1999 more than **400** women with at least one prior NTD-affected pregnancy were given folic acid. During this time period, there were 169 subsequent pregnancies. If none of these women had taken folic acid, it is likely that five

to seven would have had another baby with an NTD. However, none of the women in the project taking folic acid had a second baby with an NTD. (One of the women in the project did have a second baby with an NTD, but she had not taken folic acid as recommended.) From these data, it appears that Hispanic women who have had one baby affected by a neural tube defect can significantly increase their chances of later having a healthy baby by taking folic acid.

Compared to women who have had healthy babies, women who have had a baby with an NTD are more likely to have:

- low vitamin B₁₂ levels
- blood test result suggesting that they may later become diabetic

Other results will be finalized and distributed during 2000-2001.

NTD surveillance, research, and prevention activities **will continue** at the Texas Department of Health. The activities include the following:

- The surveillance component has been incorporated into the Texas Birth Defects Monitoring Division, as part of a permanent statewide surveillance system for NTDs and other structural malformations.
- The folic acid intervention (recurrence prevention) component will be incorporated into the Texas Birth Defects Research Center (TBDR) as part of a new statewide NTD recurrence prevention project. Currently enrolled subjects on the border will be included.
- As the TNTDP closes the enrollment for its case-control study, new NTD cases along the border will be enrolled in another ongoing statewide TBDR study of NTDs and other malformations of the central nervous system.
- Further NTD prevention efforts are being conducted in partnership with university collaborators, the March of Dimes, the Texas Folic Acid Council, and other entities.

The effort of the devoted TNTDP staff is recognized as an example of effective public health in action.

For more information about the Texas Neural Tube Defects Project, contact Russ Larsen, Ph.D. at 512-458-7676. To find out about continuing folic acid/NTD activities in the state, contact Amy Case, Information Specialist, Texas Birth Defects Monitoring Division, 512-458-7232 or amy.case@tdh.state.tx.us.



Registry Update

Cluster Investigation Allays Birth Defects Concerns

The federal Agency for Toxic Substances and Diseases Registry (ATSDR) conducted a health assessment in areas around Kelly Air Force Base in San Antonio. Birth defects were one of the health outcomes studied. Using vital records from 1990-1995, ATSDR reported an excess of certain broad categories of heart and circulatory system defects. These were "bulbus cordis anomalies and anomalies of cardiac septal closure" (ICD-9 code 745), "other congenital anomalies of the heart" (ICD-9 code 746), and "other congenital anomalies of the circulatory system" (ICD-9 code 747).

Following that, the Texas Birth Defects Monitoring Division was asked to determine if the occurrence of birth defects was higher than expected in areas near Kelly Air Force Base, using more accurate data from the Texas Birth Defects Registry for the first year available (i.e. 1997 deliveries.)

There were no statistically significant excesses of the heart and circulatory system defect categories that were found elevated in the ATSDR report. There were significant excesses of several other broad categories of birth defects. However, the relevance of that was questionable because of the variety of defects within categories, absence of recurring patterns, and susceptibility to diagnostic and reporting biases. We then focused on more specific birth defect categories that we expect would be more uniformly diagnosed and reported across the State. There were no significant elevations noted, allaying concerns about excessive birth defects in the area.

The original ATSDR report (Petitioned Public Health Assessment, Phase I, Kelly Air Force Base, San Antonio, Bexar County, Texas, No. TX2571724333, released for public comment on Oct 26, 1999) dealt with a variety of health outcomes. For more information, contact ATSDR. Disease Registry, Division of Health Assessment and Consultation, Att: Chief, Program Evaluation, Records, and Information Services Branch, E-56, 1600 Clifton Road, N.E., Atlanta, Georgia 30333, phone 888-42ATSDR, San Antonio Metropolitan Health District 210-207-8853, or the Texas Department of Health 512-458-7269.



Prevention Notes

News from the Texas Teratogen Information Service

The Texas Teratogen Information Service (TTIS) was established in 1991 to provide free teratogen counseling to the residents of Texas, and is currently in its ninth year. The service is located at the University of North Texas, but serves callers throughout the state.

Concerned Texans and their health care providers can call the TTIS and get up-to-date information about various substances or potential environmental toxins to which a pregnant woman may have been exposed.

Texas Teratogen Information Service
1-800-565-3892

Nearly fifteen hundred calls were received between September 1, 1999-March 31, 2000. More than 60% of calls received were regarding concerns about prescription medication or work-related exposures. Besides answering inquiries, this year TTIS has enhanced their outreach efforts targeted toward teenagers. A grant from the North Texas Chapter of the March of Dimes enabled TTIS staff to make presentations to 1000 high school students in the north Texas area. The staff also promoted the service to college students at health fairs. TTIS attributes a 1% increase in calls to the 800 number (a 5% increase in calls from the general public) to this increase in public education.

Individuals or health care providers interested in finding out about potential teratogens are encouraged to call 800-733-4727 or 940-565-3892. Organizations may also call this number to arrange for a presentation by TTIS.

Folic Acid Poll Results

Despite years of public health campaigns advising that taking the B vitamin folic acid helps prevent serious birth defects of the brain and spine, most women of childbearing age are still not taking the vitamin in time, according to a national survey released by the March of Dimes.

Only 32 percent of women between the ages of 18 and 45 who were not pregnant at the time of the survey took a daily multivitamin containing folic acid. This figure has increased only slightly since 1995, the first year the March of Dimes surveyed women. This despite the fact that 75 percent of women say they are aware of folic acid, up from 52 percent in 1995.

Half of the women aware of folic acid say they learned about it from a magazine or newspaper article or a radio or television broadcast. One in 5 women (20 percent) say their physician or other health care provider told them about the



Research Center

Texas BRFSS Targets Folic Acid

The Texas Behavioral Risk Factor Surveillance System (BRFSS), initiated in 1987, is a federally funded telephone survey conducted on a monthly basis of 1500 randomly selected adult Texans to collect data on lifestyle risk factors contributing to the leading causes of death and chronic diseases. As part of the national BRFSS, Texas can select from a list of standardized questions, known as optional modules, that are asked of a specific target population. In 1999 and 2000, the Texas Birth Defects Research Center (TBDRC) has funded the use of a folic acid module. This module includes standard questions predetermined by the Centers for Disease Control and Prevention, plus two questions written by the TBDRC.

The standard folic acid module provided by the CDC can be found at <http://www.cdc.gov/nccdphp/brfss/brfsques-questionnaires.htm>, in the 2000 Survey Questions. The

questions supplied by the TBDRC are:

- "Has a doctor or nurse ever advised you to take multivitamins or supplements?"
- "What would you say is the main reason that you do not take any vitamin pills or supplements?"

Preliminary data from the 1999 survey provide some interesting insights to the awareness and behavior of Texas women regarding folic acid. For example:

Educational attainment is strongly correlated with the following: the woman's awareness of folic acid and birth defects, daily folic acid supplementation, and whether a health care provider ever advised her to take a vitamin or supplement.

Although the survey provided a choice of four pre-written answers to the second question above, more than half gave another answer or responded "Don't know". Analysis of these reasons given will provide a rich resource for designing folic acid awareness strategies in Texas.

Data tables and additional information will be available on the Texas Birth Defects Monitoring Division by September 1, 2000, at www.tdh.state.tx.us/tbdmd/index.htm. Please address requests for printed information to Amy Case at 512-458-7232.



AS Corner

Substance abuse treatment options in Texas for pregnant woman

Some studies have shown that one-third to one-half of pregnant women identified as "moderate to heavy drinkers" were able to cut their alcohol consumption significantly when they received counseling about the hazards of alcohol to their fetus. However, it is the group of women who continue to abuse alcohol who are at greatest risk for giving birth to a baby with an alcohol-related birth defect. For these women, the existence of services appropriate to their special needs is crucial to limit the damage to their unborn babies as early as possible.

What are the special needs of pregnant women seeking alcohol and drug abuse treatment? The National Clearinghouse for Alcohol and Drug Abuse Information recommends that treatment programs serving pregnant women include or actively link to the following:

- Comprehensive inpatient and outpatient treatment on demand
- Comprehensive medical services
- Gender-specific services that are ethnically and culturally sensitive.
- Transportation services, including cab vouchers, bus tokens, and alternatives where appropriate public transportation

is unavailable

- Child care, baby-sitting, and therapeutic day care services for children
- Counseling services, including individual, group, and family therapy
- Vocational and educational services
- Drug-free, safe housing
- Financial support services
- Case management services
- Pediatric follow-up and early intervention services
- Services that recognize the unique needs of pregnant adolescents

The Texas Council on Alcohol and Drug Abuse (TCADA) requires that programs funded as specialized female services arrange to meet these special needs. In addition, women with children and pregnant or postpartum women must receive priority admission to treatment programs.

TCADA currently funds 42 programs that accept pregnant and postpartum women. In 1999, these programs provided services to 660 pregnant women, which representst 4.5% of the women served and 1.6% of all clients.

A list of the TCADA-funded programs that provide services for pregnant women can be obtained from Judy Brow at 512-349-6626, E-mail: Judy_Brow@tcada.state.tx.us. Also, a search tool that can locate substance abuse treatment programs nationwide can be found on the Substance Abuse and Mental Health Services Administration (SAMHSA) web site under the "Advanced" options at <http://www.dasis.samhsa.gov/UFDS/welcome.htm>



Living with Birth Defects

The Cost of "Hidden" Birth Defects

For the purposes of birth defects registries, a birth defect must be diagnosed before the end of the first year of life (except Fetal Alcohol Syndrome). The March of Dimes defines a birth defect as "any anomaly, functional or structural, that presents in infancy or later in life and is caused by events preceding birth, whether inherited, or acquired." Although registries are focused on the birth defect recognized prenatally or in the first year of life, it may be helpful to examine the consequences and outcomes of congenital anomalies that present "later in life" as defined by the March of Dimes.

Structural and genetic defects such as those collected by most birth defect registries are most often identified at birth, during the first year, or even before birth through increasingly sophisticated prenatal testing. Nevertheless, congenital anomalies can remain hidden and undiagnosed well into adulthood. These anomalies can have a significant impact on the lives of the people who experience them.

"Jane" is a 27-year-old social worker. Born with *uterus didelphys*, or "double uterus" (müllerian fusion defect), this condition remained undiagnosed until she was 18, despite routine gynecologic exams since age 16. Without a diagnosis, the menstrual difficulties she experienced resulted in embarrassment and confusion. Receiving a correct diagnosis addressed these problems, but opened the door to others. At 22 and preparing to marry, Jane pursued a more thorough explanation of her anomaly because of concerns for future childbearing. "I was so concerned, I contemplated not telling my fiancé . . . I was not accepting the diagnosis, so I was anticipating that no one else would be."

Jane's concerns for future pregnancies are not unfounded. Although women with müllerian anomalies can and do carry healthy babies to term, these anomalies are associated with sterility, spontaneous abortion, fetal growth retardation, and perinatal mortality. This is an example of a defect not immediately visible and that does not cause any symptoms until puberty, so is not included in rates of birth defects. However, correct identification of a uterine defect would be essential in the management of menstrual difficulties, pregnancy, and infertility.

At the age of 25 Rhonda Alvaredo, a computer support technician, was diagnosed with Arnold Chiari malformation type I (herniation of the cerebellar tonsils into the foramen magnum) and syringomyelia. For years she had sought answers to the symptoms that plagued her: leg pain, headaches unresponsive to treatment, and loss of feeling in the hands and arms. Throughout her life, these symptoms had been diagnosed as everything from inner ear infections to hyperthyroidism.

Unlike the Type II Chiari malformation, Type I Chiari is not associated with spina bifida. Therefore, this defect can remain hidden throughout a person's life unless symptoms lead to its identification. For example, in one study, 76% of patients presenting with idiopathic scoliosis were diagnosed by MRI as having Chiari I malformation. Despite its hidden nature and late diagnosis, however, the symptoms are still attributable to a birth defect.

Much media attention has been directed at another type of birth defect that often remains undiagnosed until late teens or adulthood: a congenital heart defect discovered when an apparently healthy young athlete suddenly collapses and dies while performing. One study found that 36% of such deaths were caused by hypertrophic cardiomyopathy, a birth defect involving heart muscle enlargement and an overly vigorous heartbeat. Hypertrophic cardiomyopathy is often inherited.

No estimates are available for the rate of major but unrecognized birth defects among adults. However, in Texas congenital anomalies rank 21st among causes of

References and additional resources about hidden birth defects:

- Border, H, Strauss, RP: Self-concept of early primary school age children with visible or invisible defects. *Cleft Palate J* 23:114, 1989
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- Sarwer et al.: Adult Psychological functioning of individuals born with craniofacial anomalies. *Plas Reconstr Surg* Feb;103(2):412, 1999
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Hidden Defects, Continued from page 4

death for adults, and seventh among young people ages 14-21.

For the adult who has been diagnosed with a birth defect, growing up without awareness of the defect is a mixed bag. Visible defects have the most impact on a child's self-esteem and social development, and even for the child with a diagnosed but unapparent defect, the knowledge that "something wrong with me" can also have an impact. As Jane put it, "I think the difficulty of finding out about my birth defect during college (led to) questioning and self-doubt about my identity. However, I feel that I have integrated it into my self-vision and now look at it as something that makes me even more unique and interesting!"

The advantages of an awareness of possible congenital malformations in the treatment of seemingly intractable symptoms should be obvious: an accurate diagnosis of a condition is the key to effective and efficient treatment of symptoms. In undiagnosed cardiac anomalies in athletes, identification and disqualification of athletes through screening may prevent the associated deaths.

Additional research into the types and rates of these "hidden" birth defects, coupled with enhanced education and awareness efforts directed toward all health care professionals, could decrease frustrating situations as described above.

—Amy Case, Editor

Children's Trust Fund of Texas Inventory of Family Resource Programs in Texas

A searchable database is available at the web site of the Children's Trust Fund of Texas at <http://www.ctf.state.tx.us/>. Users can select one or more services, city and/or county and will be given a list of programs meeting the request, with contact information. Services range from case management of professional training to substance abuse counseling, and many more.

Survey, Continued from page 2

vitamin.

"Physicians and other health care providers should use every contact with women of childbearing age as an opportunity to teach them about the benefits of daily folic acid," said Dr. Jennifer Howse of the March of Dimes. "This survey should be a call to action for every doctor, nurse, and midwife."

The March of Dimes is in the second year of a \$10 million, multi-year national folic acid education campaign aimed at reducing the incidence of neural tube defects by at least 30 percent by the year 2001. The current campaign includes new

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print and broadcast public service advertisements (PSAs). Locally, the campaign has funded efforts of the Texas Folic Acid Council (TFAC). The TFAC will be distributing folic acid "starter kits" to women of childbearing age statewide, and will ensure that PSAs receive adequate coverage in Texas media.

This survey follows up three previous March of Dimes polls of women's knowledge and behavior on issues related to healthy pregnancy. It was conducted for the March of Dimes by The Gallup Organization under a grant from the Centers for Disease Control and Prevention. The results are based on telephone interviews with a national sample of 2,013 women age 18 to 45 conducted from January 13 to February 17, 2000.

Copies of the March of Dimes survey results, "Folic Acid and the Prevention of Birth Defects," can be obtained by calling 1-800-367-6630.

For information about the Texas Folic Acid Campaign, call Amy Case at the Texas Birth Defects Monitoring Division, 512-458-7232 or Sylvia Salas, March of Dimes Central Texas Chapter, 512-477-3221.



Regional Bulletin

On March 28, 2000, the Region 2/3 Birth Defects Monitoring staff experienced an unforeseen crisis—the Texas Department of Health building in Arlington, Texas was destroyed by a tornado that rated F3 on the Fujita damage scale, with winds estimated at 158 to 206 mph. The tornado tore away most of the building's roof, ceilings and synthetic stucco walls, leaving little more than the steel frame.

Thankfully, the storm hit after work hours, so no one was injured as few people were in the building. The next morning staff found the north and east outer walls completely gone.

(See photo). Debris was scattered throughout the parking lot, and in adjacent lots. State vehicles were found far from where they had been parked the day before. The area of the building that shares a wall with Birth Defects was severely damaged. However, the shared wall remained intact and the Birth Defects office suffered only water damage. Computers and data were recovered for the Birth Defects program. Surveillance activities will continue, with some delays possible. At this writing the regional program has secured temporary space that is adequate for the basic needs of the program. Watch our web site for updates on contact information. The regional program would like to thank everyone for your help, patience and understanding during this crisis.





Staff Highlights

We are pleased to introduce a new feature to the Texas Birth Defects Monitor that will focus on the frontline work done by our surveillance staff, and the people who do that work.

Mary Lou Marez is a Surveillance Specialist with the Texas Birth Defects Monitoring Division, Region 7

Mary Lou majored in child development in college, then worked as a Head Start Director for eight years. Mary Lou began her career in public health with the Immunization Division's "Shots Across Texas" campaign. She has since had experience in the WIC Bureau of Nutrition Services and Texas Health Steps, doing outreach in the community both for Medicaid participants and professional participants.

Q: How did you become involved in birth defect surveillance?

A: One of my previous supervisors at WIC was the Field Supervisor for the Texas Birth Defects Monitoring Division. I immediately applied for the position. I have always been fascinated with epidemiologists and their work. I was hoping to be a part of it.

Q: When someone asks you what you do, how do you describe it?

A: I am a surveillance specialist with Texas Birth Defects Monitoring Division which is under the Bureau of Epidemiology. I collect data from hospital records on birth defects. I visit hospitals and review their records on all births that may indicate the infant may have been born with a birth defect. We collect the data that is then placed into a database and reviewed by others who conduct investigations of birth defect clusters throughout the state.

Q: What is the most important contribution that the Texas Birth Defects Monitoring Division makes to public health or the state?

A: The data collected is vital because, without this data, the research, the knowledge of prevention or the services to the families would not be possible. Giving this information to the public is important so that they can be educated on the issues of birth defects and the state can help find prevention methods with others.

Q: What is our most significant future challenge/opportunity as a Division?

A: Maintaining well-trained staff in all areas so that TBDMD can function at a higher professional level.

Q: What do you like best about your job?

A: The freedom of managing the hospitals assigned to me and incorporating my own style of work.

Note: The Texas Birth Defects Monitoring Division employs more than 30 Surveillance Specialists throughout the state. These public health technicians must be knowledgeable in the areas of medical coding, records, and terminology;

anatomy, physiology, and embryology; be highly detail oriented, and be able to quickly learn and apply computer applications.



Reading List

Neural Tube Defects (NTDs) and Folic Acid: An investigation in China found that preconception consumption of folic acid alone can reduce NTD risk. This reduction was particularly pronounced in a region with high NTD rates. [N Engl J Med 1999;341:1485-1490]

Fetal Surgery and Spina Bifida: Two studies by researchers in Tennessee and Pennsylvania, respectively, found that fetal surgery for repair of spina bifida appear to reduce the degree of hydrocephaly and hindbrain herniation in the infant. An accompanying editorial discussed history, progress, and problems associated with fetal surgery. [JAMA 1999;282:1819-1825. JAMA 1999;282:1826-1831. JAMA 1999;282:1873-1874]

Oral Clefts and Folic Acid: Researchers in Hungary reported that consumption of folic acid at the critical period of gestation when oral clefting occurs can reduce the risk of having an infant with an oral cleft. However, this reduction is dose-dependent, with high doses needed to affect risk, especially for subsequent pregnancies. [Pediatrics 1999;104:e66]

NTDs and Folic Acid: Researchers with various programs around the world evaluated trends in NTD rates and found no decline in rates that could be accounted for by folic acid programs. [J Epidemiol Community Health 1999;53:630-635]

Holoprosencephaly and Risk Factors: A case-control study in California found a suggestion of an association between cytogenetically normal holoprosencephaly (a malformation of the brain) and maternal alcohol, smoking, insulin-dependent diabetes, respiratory illness medications, and salicylate-containing medications. [Am J Med Genet 2000;90:320325]



Announcements

Conference Proceedings Available

Proceedings from the Texas Birth Defects Conference 2000 can be obtained in Adobe PDF format at the TBDMD web site, <http://www.tdh.state.tx.us/tbdmd/index.htm>. Hard copies are also available by contacting Amy Case at 512-458-7232, amy.case@tdh.state.tx.us.

Directory of Resources for People with Facial Differences

Let's Face It, an information and support network for people

with facial differences, families and professionals, has released their 2000 resource guide. For more information, call 360-676-7325. The web site is <http://www.facit.org/letsfaceit/>

National Legislation

Children's Health Act of 2000 (HR4365): The Children's Health Act passed the House on May 9. This legislation is a compilation of many bills that have been introduced and addresses a variety of children's health issues, including: Fragile X, birth defects prevention, traumatic brain injury, asthma, autism, Type II diabetes, and early infant hearing screening. The bill has now been sent to the Senate and placed on the calendar.

Women Vietnam Veterans' Children's Birth Defects Benefits Act (H.R.4488 and S.2544): These bills have been introduced to amend title 38, United States Code, to provide benefits for children of women Vietnam veterans who suffer from certain types of birth defects.



alendar

July 21-23, 2000 Texas School for the Deaf Family Retreat. Speakers, information exchange, support groups, and recreation for families with deaf and hard of hearing children. Call 512-462-5300

August 25-26, 2000 Texas Fiesta Educativa, San Antonio. A statewide conference that promotes working with Hispanic parents of children with disabilities. Call Alba A. Ortiz, 512-471-6244

September 14 - Neonatal Nurses Day

September 14-16, 2000 International Clearinghouse for Birth Defects Monitoring Systems, 1st International Symposium on Prevention and Epidemiology of Congenital Malformations Cardiff, UK. For more information, phone +44-207-5335209 or e-mail: lorraine.streater@ons.gov.uk.

September 20-24, 2000 American Academy of Family Physicians 2000 Scientific Assembly. For more information, send e-mail to assemblyinfo@aafp.org or call 1-800-926-6890.

October 2000 - National Campaign for Healthier Babies Month

October 2000 - National Spina Bifida Prevention Month

Tuesday, January 9, 2001, 77th Texas Legislature convenes

January 29-31, 2001 National Birth Defects Prevention Network Meeting, San Antonio. Contact Kerda DeHaan (502) 564-7818, ext. 3763, e-mail: kerda.dehaan@mail.state.ky.us

March 2002, Texas Birth Defects Biennial Conference, Dallas/Ft. Worth. Contact Amy Case, phone: 512-458-7232, e-mail: amy.case@tdh.state.tx.us



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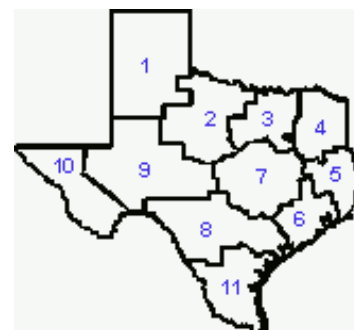
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To be added to the mailing list for this or other free publications from the Division, please contact us at (512) 458-7232 or e-mail bobbie.mankowski@tdh.state.tx.us.



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